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Citation for published version:
on behalf of Project PRISMA, Higginson, IJ, Gomes, B, Calanzani, N, Gao, W, Bausewein, C, Daveson, BA, Deliens, L, Ferreira, PL, Toscani, F, Gysels, M, Ceulemans, L, Simon, ST, Cohen, J & Harding, R 2014, 'Priorities for treatment, care and information if faced with serious illness: a comparative population-based survey in seven European countries', *Palliative Medicine*, vol. 28, no. 2, pp. 101-10. https://doi.org/10.1177/0269216313488989

Digital Object Identifier (DOI):
10.1177/0269216313488989

Link:
Link to publication record in Edinburgh Research Explorer

Document Version:
Publisher's PDF, also known as Version of record

Published In:
Palliative Medicine

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Palliative Medicine
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Palliat Med 2014 28: 101 originally published online 23 May 2013
DOI: 10.1177/0269216313488989

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PALLIATIVE MEDICINE

Palliative Medicine
2014, Vol 28(2) 101–110
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DOI: 10.1177/0269216313488989
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Priorities for treatment, care and information if faced with serious illness: A comparative population-based survey in seven European countries

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Abstract

Background: Health-care costs are growing, with little population-based data about people's priorities for end-of-life care, to guide service development and aid discussions.

Aim: We examined variations in people's priorities for treatment, care and information across seven European countries.

Design: Telephone survey of a random sample of households; we asked respondents their priorities if 'faced with a serious illness, like cancer, with limited time to live' and used multivariable logistic regressions to identify associated factors.

Setting/participants: Members of the general public aged ≥16 years residing in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain.

Results: In total, 9344 individuals were interviewed. Most people chose 'improve quality of life for the time they had left', ranging from 57% (95% confidence interval: 55%–60%, Italy) to 81% (95% confidence interval: 79%–83%, Spain). Only 2% (95% confidence interval: 1%–3%, England) to 6% (95% confidence interval: 4%–7%, Flanders) said extending life was most important, and 15% (95% confidence interval: 13%–17%, Spain) to 40% (95% confidence interval: 37%–43%, Italy) said quality and extension were equally important. Prioritising quality of life was associated with higher education in all countries (odds ratio = 1.3 (Flanders) to 7.9 (Italy)), experience of caregiving or bereavement (England, Germany, Portugal), prioritising pain/symptom control over having a positive attitude and preferring death in a hospice/palliative care unit. Those prioritising extending life had the highest home death preference of all groups. Health status did not affect priorities.

Conclusions: Across all countries, extending life was prioritised by a minority, regardless of health status. Treatment and care needs to be reoriented with patient education and palliative care becoming mainstream for serious conditions such as cancer.

Keywords

Decision making, cross-cultural comparison, life extension, palliative care, quality of life

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Introduction

Innovations and new treatments mean that intensive treatments are increasingly offered in advanced illness. As a result, about a quarter of health-care expenditure is incurred for people in the last year of life.[1,2] The costs of cancer treatment and care are predicted to increase in the United States to over US$173 billion in 2020 and beyond, increasing by 600% in 30 years.[3] This rise in costs is echoed in most countries and across many diseases, driven by the growing prevalence of cancer and chronic conditions in ageing populations and the high costs of new intensive treatments. Recent criticism proposes that a shift is needed to limit intensive second- and third-line chemotherapies with little proven benefit on survival, accompanied by change of attitudes and practices.[4,5]

Intensive treatment in advanced illness is often given in the belief that patients and their families wish for survival to preserve hope. However, what are the actual patient and public views? Current evidence is conflicting, ranging from 40 out of 95 patients attending a London cancer centre believing that they would choose intensive treatment for a 3-month increase in survival or symptom relief[6] to 84% of 147 older adults attending centres in the United States, preferring medical care focused on comfort rather than focused on extending life.[7] Data from specific centres are unlikely to represent general opinion and vary by setting and question format. While some intensive treatments are given primarily for symptom relief, some have profound side effects or restrict patients' interactions or activities, affecting quality of life.[4,6] To ensure appropriate future health-care delivery in the face of rising costs, robust information on public priorities and preferences is pressing. Furthermore, we need to understand how priorities are influenced by individual characteristics and by country, where cultures, religious beliefs, provision of palliative care services and legal frameworks vary.[8,9] This study aimed to examine citizens' priorities if faced with a serious illness, like cancer, and limited time to live, across seven European countries, and to identify overall and country-specific influencing factors.

Subjects and methods

This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines,[10] and the completed checklist for cross-sectional studies is available online (Table A in supplementary data).

Design and participants

This population-based telephone survey covered England, Flanders (the Dutch-speaking part of Belgium), Germany, Italy, the Netherlands, Spain and Portugal. These countries were chosen as they took part in a European collaborative (PRISMA) that had the aim to co-ordinate research into end-of-life care in cancer.[11] Each country/region has between 10 and 81 million inhabitants, diverse sociodemographic profiles and palliative care services[9] (Table B in supplementary data). Portugal, Italy and Spain have a strong influence of the Catholic Church, a common tendency for partial disclosure of diagnosis and low use of advance directives compared to north European countries.[12] In Flanders and the Netherlands, there is a culture of full disclosure and euthanasia is legal since 2002.[13,14] In England, specialist palliative care services are most strongly established, and there is a national end-of-life care strategy aiming to raise public awareness and challenge taboos about death.[8,15] In Germany, there is an attitude of full disclosure regarding diagnosis, and non-compliance with advance directives has recently become a legal offence.[16]

Individuals aged ≥16 years residing in a household were invited to participate in a computer-assisted telephone interview (CATI) by a random selection of households using random digit dialling (RDD). Exclusion criteria were incapacity to hear or understand the information and provide informed consent (assessed by the interviewers) and poor language skills that precluded them from participating in the survey in the dominant language in each respective country.

Procedures

To ensure standardisation and high-quality data, we developed comprehensive manuals and trained 149 interviewers (95% native speakers) with experience in telephone surveys on social and health issues to administer our questionnaire. Interviews were conducted from May to December 2010 with at least four call attempts (at least one made after 6 p.m. to capture working adults).[17]

The questionnaire was developed and revised following review of studies and questions on preferences and priorities for end-of-life care[18] and three consultation rounds of individual feedback and group discussions with 27 experts who were partners in the study.[11] The questionnaire had 28 questions (available online as supplementary data) and could be completed in 15 min on the telephone. It was piloted using cognitive interviewing, a well-established approach when developing surveys[19,20] with a purposeful sample of 30 volunteers in England and Germany.[21] The questionnaire was translated into each country's dominant language by forward translations by two independent native speakers, backward professional translation and harmonisation of all versions, following European Organisation for Research and Treatment of Cancer (EORTC) translation procedures.[22] Three questions addressed priorities (Box 1) regarding treatment, personal care and information/decision-making. Other questions included social and demographic backgrounds (with questions adapted from the

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European Social Survey[9]) and also end-of-life experiences. Publications on other topics covered by the questionnaire are available.[17,23–26]

Telephone surveys have been helping public health research and practice for decades;[27] this method was also the most cost-effective to obtain a random sample of households. The interviews were carried out using CATI; this involves the use of software that allows the questionnaire to be displayed on the screen in a standardised way. Households were selected via RDD; telephone numbers were generated by adding random numbers to real area dialling codes in each country. No quotas (geographic or sociodemographic) were applied. The questionnaires were piloted over the telephone in all the countries (485 interviews in 16 days) to test the feasibility and acceptability of methods; no changes were made after piloting.

Ethical approval

King's College London Research Ethics Committee approved the study (ref: BDM/08/09-48). We obtained local ethics approvals and notified data protection agencies in all participating countries. Participants gave verbal consent to interview and could stop at any time. Local support was offered if individuals became distressed, following a protocol for managing respondent distress.

Statistical analysis

We described and compared responses using percentages with 95% confidence intervals (CIs). We tested for differences using Mann–Whitney *U* tests, *t*-tests, Pearson and Cochran–Mantel–Haenszel χ^2 tests as appropriate. Logistic regression was used to verify the relationship between potential explanatory demographic variables and respondent preference at the end of life (dependent variable in binary scale, coded as 1 = improve quality of life for the time left; 0 = extend life or both equally important). All available explanatory variables were forced to stay in the model. The overall model fit was assessed by using Likelihood ratio test. The Max-rescaled R^2 was derived to assess the total variation explained by the model. We fitted separate models for each individual country. Descriptive analyses used SPSS 17 for Windows, modelling analyses SAS statistical software, version 9.2. Cases with missing data were excluded. Tests were two-tailed and $p \leq 0.05$ was deemed significant. We aimed for a minimum of 1278 completed interviews in each country to allow us to detect a 9% difference (power = 0.90, significance = 0.05) in preferences or priorities between groups.[17]

Results

Response rates and sample characteristics

From 45,242 randomly selected households with a known eligible person, 9344 people (21%) agreed to participate in the study. The response rate was highest in Germany (29%), followed by Portugal (28%), Spain (21%), Italy (21%), England (21%), Flanders (16%) and the Netherlands (16%). Our samples were broadly representative of each country in terms of age, gender and social situation (Table 1), although there was a high proportion of women responding. Main reasons for refusing to participate were lack of interest (59%) and lack of time (17%); further information on refusal reasons is available elsewhere.[17]

Box 1. Questions about treatment, care and information/decision-making priorities in the PRISMA survey.

1. When people are faced with a serious illness like cancer with limited time to live, they may have to make difficult decisions and prioritise some things over others. In this situation, would it be more important to extend your life or to improve the quality of life for the time you had left? READ OUT AND CODE ONLY ONE.
   □ To extend life
   □ To improve the quality of life for the time you had left
   □ Both are equally important
2. When people are faced with a serious illness like cancer with limited time to live, they may have to make difficult decisions and prioritise some things over others. In this situation, how would you order the following four aspects by their level of importance to you, the first being the most important (1) and the last being the least important (4)?
   Aspects RANK 1 = MOST IMPORTANT/4 = LEAST IMPORTANT
   A – Keeping a positive attitude
   B – Having pain and discomfort relieved
   C – Having practical matters resolved
   D – Making sure relatives and friends are not worried or distressed

(Box1 Continued)

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Box 1. Continued

3. What would matter most to you in the care available? Please choose from the following three aspects the one that would matter most to you. And in second place?

   - Having as much information as you want
   - Choosing who makes decisions about your care
   - Dying in the place you want

Public priorities for treatment, cancer and information

In all countries, the treatment priority was for improving the quality of life for the time left rather than extending life (Table 2). This ranged from 81% (95% CI: 79–83) in Spain to 57% (95% CI: 55–60) in Italy. In all countries, only a small proportion wanted to extend life, ranging from 2% (95% CI: 1–3) in England to 6% (95% CI: 4–7) in Flanders. Overall, one in four respondents thought that extending life and quality were equally important; this varied between countries from 15% (95% CI: 13–17) in Spain to 40% (95% CI: 37–43) in Italy.

Of the four possible care choices, across the seven countries, having pain and discomfort relieved and keeping a positive attitude were equally prioritised the highest (36%, 95% CI: 35–37), followed by relatives/friends not being worried or distressed (20%, 95% CI: 19–21) and practical matters resolved (9%, 95% CI: 9–10). However, the priority of these goals varied by country, with keeping a positive attitude rated as highest priority in Flanders, Germany, Italy and the Netherlands, and pain and discomfort relieved rated highest in England and Portugal. In Italy, 36% (95% CI: 33–38) chose family/friends not being worried or distressed (Table 2).

These personal care choices were significantly associated with prioritising life extension or life quality. After adjusting for country differences, those who prioritised extending life were more likely to rank keeping a positive attitude and making sure friends and relatives are not distressed as most important (Table 3). Conversely, those who prioritised quality of life were more likely to rank having pain and discomfort relieved and having practical matters resolved as most important. Home death was the most preferred option overall (69% of respondents), and it was more common in those prioritising extending life (74%) versus those choosing quality of life (67%). Preference for hospice or palliative care unit was much higher in those choosing quality of life (21%) versus those choosing life extension (9%) (Table 3). Overall, the highest priorities for information and decision-making were almost equal for having as much information as wanted (37%, 95% CI: 36–38) and dying in the preferred place (36%, 95% CI: 35–37), slightly lower was choosing who should make decisions about care (29%, 95% CI: 28–30). Germany and the Netherlands ranked dying in the preferred place (42% and 41%, respectively) the highest, and Germany ranked having as much information as wanted (24%) lowest (Table 2). There was no relationship between these options and whether the respondent preferred life extension or improving quality of life (Table 3).

Factors associated with treatment priorities

Logistic regression analysis found variation between countries in demographic factors associated with respondents' treatment priority of improving quality of life (Table 4). Therefore, it was not appropriate to develop an overall model across countries. In England, seven characteristics (men, married rather than widowed, living alone, no religious belief, good financial status, the experience of close relative's death and the experience of caring for a relative in the past 5 years) were independently associated with prioritising quality of life; while in Germany, only the experience of caring for a close relative in the past 5 years mattered (odds ratio $(OR)_{yes\ vs\ no} = 1.6$; 95% CI: 0.2–2.1). In Italy, Portugal and Spain, older age was a significant predictor of prioritising quality of life. A higher education level was associated with prioritising quality of life in all countries (ORs range: 1.3–7.9) and reached a statistically significant level in Flanders, the Netherlands, Portugal and Spain. In all countries, the respondent's health status or country of birth were not independent predictors of treatment priority.

Discussion

Common across all countries was the public's low priority for extending life (less than 6% of respondents) if faced with advanced cancer. The most popular priority was quality of life (57% or more of respondents). The largest variation between countries was observed in whether respondents felt that both quality and life extension were equally important, with 40% in Italy compared to 15% in Spain choosing this option. The consistent emphasis on quality of life, either alone or with life extension, has implications for cancer treatment and care. Survival rates remain low even from diagnosis for some common cancers (such as lung and pancreas), especially when metastatic disease is present.[4,28] Asking patients, soon after diagnosis, about their treatment

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Table 1. Survey participant characteristics by country.

	England (*N* = 1351)	Flanders (*N* = 1269)	Germany (*N* = 1363)	Italy (*N* = 1352)	Netherlands (*N* = 1356)	Portugal (*N* = 1286)	Spain (*N* = 1367)	All countries (*N* = 9344)
Age								
Mean in years (SD)	54.2 (16.3)	52.2 (14.7)	47.1 (15.7)	48.7 (15.9)	54.5 (14.6)	50.1 (16.9)	48.1 (16.5)	50.7 (16.0)
Median (IQ range)	56 (42–66)	53 (44–62)	47 (36–58)	50 (38–60)	55 (45–64)	51 (38–63)	48 (36–60)	50 (40–62)
Range (minimum–maximum)	16–92	16–89	16–91	16–90	16–98	16–87	16–95	16–98
Gender								
Female	863 (63.9%)	832 (65.6%)	790 (58.0%)	974 (72.0%)	891 (65.8%)	893 (69.4%)	935 (68.4%)	6178 (66.1%)
Living arrangements								
Living alone	325 (24.2%)	197 (15.6%)	281 (20.8%)	142 (10.5%)	294 (21.8%)	136 (10.6%)	156 (11.5%)	1531 (16.5%)
Urbanisation level								
Big city or suburbs/outskirts	500 (37.1%)	289 (22.8%)	556 (40.9%)	269 (19.9%)	363 (26.8%)	643 (50.0%)	324 (23.7%)	2944 (31.5%)
Town or small city	495 (36.7%)	224 (17.7%)	419 (30.8%)	526 (39.0%)	311 (23.0%)	368 (28.6%)	589 (43.1%)	2932 (31.4%)
Country village	287 (21.3%)	591 (46.6%)	301 (22.1%)	521 (38.6%)	578 (42.7%)	221 (17.2%)	401 (29.4%)	2900 (31.1%)
Farm or home in countryside	66 (4.9%)	165 (13.0%)	85 (6.2%)	34 (2.5%)	103 (7.6%)	54 (4.2%)	52 (3.8%)	559 (6.0%)
Marital status								
Married or with a partner	822 (61.3%)	951 (75.7%)	784 (58.1%)	860 (63.8%)	932 (69.2%)	814 (63.6%)	847 (62.2%)	6010 (64.8%)
Divorced or separated	175 (13.1%)	100 (8.0%)	152 (11.3%)	86 (6.4%)	110 (8.2%)	91 (7.1%)	100 (7.3%)	814 (8.8%)
Widowed	131 (9.8%)	96 (7.6%)	83 (6.2%)	92 (6.8%)	142 (10.5%)	109 (8.5%)	113 (8.3%)	766 (8.3%)
Single	212 (15.8%)	110 (8.8%)	330 (24.5%)	310 (23.0%)	162 (12.0%)	265 (20.7%)	301 (22.1%)	1690 (18.2%)
Religion/denomination								
With a religion or denomination	778(57.9%)	664 (52.9%)	771 (57.0%)	1094 (81.6%)	616 (45.6%)	1017 (79.6%)	959 (71.0%)	5899 (63.6%)
Where born								
Born in country where survey is taking place	1201 (89.0%)	1205 (95.0%)	1233 (90.6%)	1298 (96.1%)	1275 (94.2%)	1168 (90.8%)	1275 (93.4%)	8655 (92.7%)
Educational level								
Less than primary education	176 (13.8%)	26 (2.2%)	3 (0.2%)	5 (0.5%)	24 (1.8%)	18 (1.4%)	123 (9.1%)	375 (4.1%)
Primary to secondary education	545 (56.7%)	607 (50.2%)	833 (61.6%)	1007 (76.2%)	821 (61.1%)	962 (76.4%)	770 (56.7%)	5545 (60.7%)
Post-secondary to tertiary education	551 (43.3%)	575 (47.6%)	516 (38.2%)	310 (23.4%)	498 (37.1%)	303 (23.6%)	466 (34.3%)	3219 (35.2%)
Financial hardship								
Living comfortably with present income	585 (43.8%)	689 (55.2%)	608 (45.5%)	430 (32.2%)	813 (60.9%)	222 (17.5%)	440 (32.6%)	3787 (41.1%)
Coping with present income	576 (43.1%)	497 (39.8%)	618 (46.2%)	677 (50.7%)	441 (33.0%)	681 (53.6%)	633 (46.9%)	4123 (44.8%)
Difficult with present income	136 (10.2%)	60 (4.8%)	85 (6.4%)	203 (15.2%)	62 (4.6%)	239 (18.8%)	203 (15.0%)	988 (10.7%)
Very difficult with present income	38 (2.8%)	3 (0.2%)	26 (1.9%)	25 (1.9%)	20 (1.5%)	129 (10.1%)	73 (5.4%)	314 (3.4%)
Health								
Very good	565 (42.0%)	490 (38.6%)	310 (22.9%)	305 (22.6%)	302 (22.3%)	170 (13.3%)	293 (21.5%)	2435 (26.1%)
Good	535 (39.8%)	583 (46.0%)	699 (51.5%)	642 (47.6%)	748 (55.3%)	488 (38.1%)	560 (41.1%)	4255 (45.7%)
Fair	191 (14.2%)	176 (13.9%)	289 (21.3%)	377 (28.0%)	254 (18.8%)	558 (43.6%)	437 (32.0%)	2282 (24.5%)
Bad	47 (3.5%)	16 (1.3%)	53 (3.9%)	21 (1.6%)	43 (3.2%)	46 (3.6%)	67 (4.9%)	293 (3.1%)
Very bad	7 (0.5%)	3 (0.2%)	5 (0.4%)	3 (0.2%)	5 (0.4%)	19 (1.5%)	7 (0.5%)	49 (0.5%)
Experience of illness, death and dying								
Diagnosed with serious illness in last 5 years	172 (12.8%)	190 (15.2%)	107 (8.0%)	113 (8.4%)	137 (10.1%)	99 (7.8%)	119 (8.8%)	937 (10.1%)
Close relative/friend seriously ill in last 5 years	849 (63.1%)	760 (60.6%)	862 (64.1%)	900 (67.4%)	969 (71.8%)	728 (57.5%)	923 (68.2%)	5991 (64.8%)
Death of close relative/friend in last 5 years	949 (70.6%)	876 (69.9%)	933 (69.4%)	928 (69.3%)	1036 (76.7%)	771 (60.9%)	1006 (74.4%)	6499 (70.3%)
Cared for close relative/friend in last months of life	679 (50.6%)	625 (49.9%)	647 (48.0%)	815 (60.8%)	702 (52.0%)	673 (53.2%)	771 (57.0%)	4912 (53.1%)

SD: standard deviation; IQ: interquartile.
The values are represented as *n* (%) unless indicated. Sums may not always amount to the total sample number because of missing values on variables. Percentages may not always add up to 100 because of rounding.

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Table 2. Priorities in treatment, care goals, information and decision-making.

	England (*N* = 1351)	Flanders (*N* = 1269)	Germany (*N* = 1363)	Italy (*N* = 1352)	Netherlands (*N* = 1356)	Portugal (*N* = 1286)	Spain (*N* = 1367)	All countries (*N* = 9344)
Treatment priority: would it be more important to extend your life or to improve the quality of life for the time you had left?								
Improve quality of life	65 (63–68)	75 (73–78)	73 (70–75)	57 (55–60)	76 (74–78)	70 (67–72)	81 (79–83)	71 (70–72)
Both equally important	32 (30–35)	19 (17–21)	23 (21–25)	40 (37–43)	20 (18–22)	26 (24–28)	15 (13–17)	25 (24–26)
Extend life	2 (1–3)	6 (4–7)	4 (3–5)	3 (2–4)	4 (3–5)	4 (3–6)	4 (3–5)	4 (3–4)
Care priority: goal was the most important priority of four personal care options								
Keeping a positive attitude	25 (23–28)	39 (36–41)	37 (35–40)	37 (35–40)	41 (39–44)	38 (35–41)	35 (32–37)	36 (35–37)
Pain and discomfort relieved	47 (44–50)	37 (35–40)	32 (30–35)	22 (20–24)	35 (33–38)	45 (42–48)	35 (32–37)	36 (35–37)
Relatives/friends not worried or distressed	20 (18–22)	19 (16–21)	17 (15–19)	36 (33–38)	13 (11–15)	12 (10–13)	22 (19–24)	20 (19–21)
Practical matters resolved	9 (7–10)	6 (5–8)	14 (12–16)	7 (5–8)	11 (9–13)	7 (6–9)	10 (9–12)	9 (9–10)
Information and decision-making: most important priority of three options								
Having as much information as you want	36 (33–38)	38 (35–41)	24 (22–27)	41 (38–44)	36 (33–38)	46 (43–49)	38 (36–41)	37 (36–38)
Choosing who makes decisions about your care	31 (29–34)	24 (22–27)	33 (31–36)	36 (33–39)	25 (22–27)	23 (21–26)	28 (26–31)	29 (28–30)
Dying in the place you want	34 (32–37)	38 (36–41)	42 (40–45)	25 (23–27)	41 (38–44)	33 (30–35)	36 (33–39)	36 (35–37)

Values are represented as crude percentages by country (with 95% CI).

Table 3. Relationship between treatment priority (improving quality of life, extending life or both equally important); care, information and decision-making preferences; and preferences for place of death, adjusting for differences between countries.

	N giving this as top priority	Improving quality of life (%)	Both equally important (%)	Extending life (%)	*p*-value (Cochrane–Mantel–Hanzel chi-squared, df)
Care options given as top priority[a]					
Having pain and discomfort relieved	3202	37.8	33.4	28.9	**<0.001 (28.0, 6)**
Keeping a positive attitude	3155	36.0	35.2	40.1	**0.008 (17.5, 6)**
Making sure relatives and friends are not worried or distressed	1716	18.1	23.3	23.7	**<0.001 (26.8, 6)**
Having practical matters resolved	799	9.3	8.9	8.8	**0.003 (19.8, 6)**
Information and decision-making options chosen as top priority[a]					
Having as much information as you want	3181	36.5	37.7	38.8	0.65 (2.5, 4)
Dying in the place you want	3054	35.7	34.2	38.3	0.67 (2.4, 4)
Choosing who makes decisions about your care	2489	29.0	29.4	23.5	0.15 (6.8, 4)
Preferred place of death[b]					
Own home or that of family member/friend	6044	66.5	69.4	73.5	**<0.001 (70.2, 12)**
Hospice or palliative care unit	1731	20.7	16.9	9.2	
Hospital (but not palliative care unit)	566	6.1	6.5	9.2	
Nursing home or residential home	195	2.1	2.1	4.3	
Other place or do not know	419	4.6	5.1	3.7	

df: degree of freedom.
The values given in boldface are significant.
[a]Cochrane–Mantel–Hanzel chi-squared tests (adjusting for between-countries differences) were carried out for each care/information/decision-making option, with a contingency table of option as first, second and third preference versus treatment priorities. Patterns for second and third choices followed those for top priorities and so are not presented.
[b]Single chi-squared test of most preferred place of death versus treatment priority.

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Table 4. Factors independently associated with people's treatment priority of improving quality of life versus extending life or quality and life extension equally important: results of logistic regression for individual countries.

Variable	England (*N* = 1185)		Flanders (*N* = 1046)		Germany (*N* = 1180)		Italy (*N* = 1080)		Netherlands (*N* = 1225)		Portugal (*N* = 1131)		Spain (*N* = 1230)	
	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*	OR (95% CI)	*p*
Age														
16–29 versus 70+	0.9 (0.4–1.6)	0.35	1.4 (0.6–3.3)	0.51	0.6 (0.3–1.1)	0.40	0.5 (0.2–1.1)	**0.001**	0.5 (0.2–1.2)	0.12	**0.3 (0.2–0.7)**	**<0.001**	**0.4 (0.2–0.8)**	**<0.001**
29–39 versus 70+	0.7 (0.4–1.2)		0.9 (0.5–1.7)		0.6 (0.3–1.2)		**0.5 (0.3–0.8)**		0.7 (0.4–1.2)		**0.4 (0.2–0.6)**		**0.4 (0.2–0.8)**	
39–49 versus 70+	0.7 (0.4–1.1)		1.0 (0.5–1.7)		0.7 (0.4–1.2)		0.7 (0.4–1.2)		0.9 (0.5–1.5)		**0.4 (0.2–0.7)**		1.1 (0.5–2.1)	
50–59 versus 70+	0.6 (0.4–0.9)		1.3 (0.7–2.2)		0.6 (0.4–1.1)		0.8 (0.5–1.4)		1.1 (0.7–1.8)		0.8 (0.4–1.4)		1.2 (0.6–2.3)	
60–69 versus 70+	0.8 (0.5–1.2)		0.9 (0.5–1.5)		0.9 (0.5–1.7)		1.3 (0.8–2.3)		1.2 (0.7–2.0)		**0.6 (0.3–1.0)**		1.3 (0.7–2.7)	
Gender														
Female versus male	**0.7 (0.6–1.0)**	**0.034**	1.2 (0.9–1.6)	0.26	1.3 (1.0–1.7)	0.10	1.0 (0.7–1.3)	0.95	**1.4 (1.0–1.9)**	**0.026**	**1.8 (1.3–2.4)**	**<0.001**	**1.5 (1.1–2.0)**	**0.016**
Living arrangements														
Living alone versus living with others	**1.6 (1.1–2.5)**	**0.023**	1.1 (0.7–1.9)	0.64	1.1 (0.7–1.6)	0.69	1.2 (0.7–2.0)	0.59	1.0 (0.6–1.6)	0.98	1.1 (0.6–1.8)	0.80	**2.0 (1.0–3.7)**	**0.040**
Urbanisation level														
Big city versus country village/others	1.0 (0.7–1.4)	0.77	0.9 (0.6–1.3)	0.75	1.0 (0.7–1.4)	0.98	1.2 (0.8–1.7)	0.53	1.0 (0.7–1.5)	0.69	1.2 (0.9–1.8)	0.33	1.0 (0.7–1.6)	0.98
Town/small city versus country village/others	0.9 (0.7–1.3)		1.0 (0.7–1.5)		1.0 (0.7–1.4)		1.0 (0.7–1.3)		0.9 (0.6–1.2)		1.0 (0.7–1.5)		1.0 (0.7–1.5)	
Marital status														
Divorced or separate versus married with partner	1.1 (0.7–1.7)	**0.001**	**1.0 (0.6–1.8)**	**0.032**	1.1 (0.7–1.7)	0.71	1.3 (0.7–2.3)	0.43	1.0 (0.6–1.9)	0.46	0.7 (0.4–1.3)	0.74	0.5 (0.3–0.9)	0.11
Widowed versus married with partner	**0.4 (0.2–0.6)**		**2.0 (0.9–4.3)**		0.7 (0.4–1.4)		1.6 (0.9–3.2)		1.6 (0.8–3.1)		0.9 (0.5–1.7)		0.6 (0.3–1.2)	
Single versus married with partner	0.6 (0.4–1.0)		**0.5 (0.3–1.0)**		0.9 (0.6–1.4)		1.3 (0.8–2.0)		0.9 (0.5–1.6)		0.9 (0.6–1.4)		0.8 (0.5–1.3)	
With a religion/denomination														
Yes versus no	**0.7 (0.5–0.9)**	**0.010**	0.8 (0.6–1.1)	0.18	1.0 (0.8–1.4)	0.79	0.8 (0.6–1.1)	0.20	0.7 (0.5–0.9)	**0.006**	0.9 (0.6–1.2)	0.45	**0.6 (0.5–0.9)**	**0.017**
Born in country where survey is taking place														
Overseas versus in the country	1.0 (0.7–1.5)	0.98	1.3 (0.6–2.5)	0.49	1.4 (0.9–2.1)	0.14	1.2 (0.6–2.4)	0.68	1.2 (0.7–2.2)	0.50	1.5 (0.9–2.3)	0.09	**1.8 (1.0–3.2)**	**0.050**
Educational level														
Primary to secondary versus less than primary	1.2 (0.8–1.9)	0.51	**1.3 (0.5–3.2)**	<0.001	NE	1.00	6.0 (0.6–62.5)	0.07	**2.6 (1.0–6.6)**	**<0.001**	**4.8 (1.4–16.3)**	**0.039**	**1.4 (0.8–2.6)**	**0.013**
Post-secondary versus less than primary	1.3 (0.8–1.9)		**2.4 (1.0–6.1)**		NE		7.9 (0.7–83.6)		**4.7 (1.8–12.3)**		**4.8 (1.4–16.8)**		**2.2 (1.1–4.3)**	
Financial hardship														
Coping versus living comfortably	**0.8 (0.6–1.0)**	**0.020**	**0.6 (0.5–0.9)**	**0.018**	0.8 (0.6–1.0)	0.18	1.1 (0.8–1.5)	0.35	**0.9 (0.6–1.2)**	**0.040**	1.0 (0.7–1.4)	0.98	1.0 (0.7–1.4)	0.98
Difficult/very difficult versus living comfortably	**0.6 (0.4–0.9)**		**0.8 (0.4–1.6)**		0.8 (0.5–1.3)		0.9 (0.6–1.3)		0.5 (0.3–0.8)		1.0 (0.6–1.5)		1.0 (0.6–1.5)	
Health														
Very bad versus very good	3.6 (0.4–33.8)	0.26	NE*	0.71	0.1 (0.0–0.7)	0.10	2.3 (0.2–27.6)	0.34	0.3 (0.0–1.9)	0.59	1.8 (0.5–7.1)	0.17	0.1 (0.0–0.7)	0.16
Bad versus very good	2.3 (1.0–5.0)		0.6 (0.2–2.1)		0.8 (0.4–1.7)		1.0 (0.3–3.0)		1.1 (0.5–2.6)		4.1 (1.3–12.8)		1.2 (0.5–2.9)	
Fair versus very good	1.1 (0.7–1.6)		1.0 (0.6–1.6)		0.7 (0.4–1.0)		0.7 (0.5–1.0)		1.2 (0.7–1.8)		1.1 (0.7–1.8)		1.0 (0.7–1.6)	
Good versus very good	1.1 (0.8–1.4)		0.8 (0.6–1.1)		0.7 (0.5–1.0)		0.9 (0.7–1.3)		1.2 (0.8–1.6)		1.1 (0.7–1.6)		0.9 (0.6–1.3)	
Experience of illness, death and dying														
Seriously ill (yes vs no)	0.7 (0.5–1.1)	0.11	1.1 (0.7–1.7)	0.71	1.2 (0.7–2.1)	0.46	**0.6 (0.3–0.9)**	**0.029**	**0.6 (0.4–0.9)**	**0.020**	1.0 (0.7–1.3)	0.33	1.0 (0.7–1.4)	0.46
Relative seriously ill (yes vs no)	1.0 (0.8–1.3)	1.00	1.0 (0.8–1.4)	0.82	1.3 (1.0–1.8)	0.05	1.3 (1.0–1.7)	0.09	1.1 (0.8–1.5)	0.72	0.8 (0.5–1.3)	0.86	1.3 (0.7–2.3)	0.83
Close relative death (yes vs no)	**1.5 (1.1–2.0)**	0.007	1.1 (0.8–1.6)	0.47	0.8 (0.6–1.1)	0.21	1.2 (0.9–1.6)	0.24	1.2 (0.9–1.7)	0.19	**1.5 (1.1–2.0)**	**0.004**	0.9 (0.6–1.3)	0.66
Care for close relative (yes vs no)	**1.3 (1.0–1.8)**	0.033	1.2 (0.9–1.6)	0.33	**1.6 (1.2–2.1)**	**0.002**	1.2 (0.9–1.6)	0.18	1.3 (1.0–1.7)	0.07	0.9 (0.7–1.2)	0.40	1.3 (1.0–1.8)	0.08
Model fit statistics														
Variance explained (%)	7.1		7.8		6.2		7.4		9.1		10.0		11.2	
Global fit (χ^2, df)	<0.001 (62.5, 26)		<0.001 (56.4,26)		0.002 (51.9, 26)		<0.001 (60.8, 26)		<0.001 (77.3,26)		<0.001 (82.5, 26)		<0.001 (88.7, 26)	

OR: odds ratio; NE: not estimable due to small sample size in that category; df: degree of freedom. The values given in boldface are significant ($p \leq 0.05$).
ORs were derived from logistic regression, each country fits one model; all listed variables are forced to stay in the model and only complete observations are used. *p* values in the table are for overall effect of individual factors.

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priorities, in terms of life extension and/or quality, would be a valuable first step that could help to optimise treatment and care.[29] Such an approach could be included in clinical guidelines, to standardise practice.

Our results suggest that treatment in cancer and other conditions will need to shift focus to greater emphasis on life quality improvement. Clinicians will also need honed skills in symptom management and communication. Patients with advanced disease have on average 11 physical symptoms[30] and complex psychological symptoms.[31] Patients with advanced disease and their relatives frequently report concerns about communication regarding diagnosis and treatment.[32,33] Our results found that respondents consistently placed a high priority on information and decision-making, irrespective of their wish for life extension or life quality. Single-country studies in Ireland and Italy have found similar priorities.[34,35] Discussions regarding prognosis and ending treatment can be especially challenging,[33] especially since there may be an association between non-acceptance and feelings of hopelessness, a sense of suffering, depression and anxiety, along with difficulties in social relations.[36] Thus, achieving a shift towards greater emphasis on quality of life will take considerable development, including training, with changes in attitude, practice and behaviour.[4] Better integration of palliative care services might also help to achieve this, along with public education, because in many countries awareness about palliative care services is low.[34,35,37]

As might be expected, those respondents prioritising treatment to improve quality of life also more often prioritised pain and symptom control and less often keeping a positive attitude. However, some associations were counter-intuitive. Those patients most interested in life extension had the highest preference for home death. This seems paradoxical and may be difficult to achieve in practice. Intensive treatments to extend life will make home care and subsequently achieving home death difficult because often treatment will occur in hospital. However, asking about preference for place of death of patients and caregivers,[17] plus rapid response home support services, may enable patients to be cared for at home.[38,39]

A higher education level was consistently associated with a greater prioritisation of quality of life. Across European countries, high levels of education are associated with longer life expectancy.[40] Consequently, those with lower levels of education may place greater emphasis on life extension. Alternatively, quality of life may be a less common concept for individuals with a lower educational background, and they are less likely to choose something they do not understand. However, our finding is the opposite of a Dutch public survey, where respondents with lower educational levels preferred quality over length of life.[41]

Despite consistency in general patterns, there were differences between countries and little consistency in the influencing factors. The two countries that lie in North Europe and have legalised euthanasia, Belgium (Flanders part) and the Netherlands, were similar to or higher than others in prioritising life extension (although it was still low – 6% and 4%, respectively). These countries might have been expected to place a high priority on who makes decisions about care but in fact were at the lower end of prioritising this (only 24% and 25%, respectively) compared to England (31%), Germany (33%) and Italy (35%) nor were the factors that influenced treatment choices, apart from education, similar across these two countries. The three south European countries – Italy, Portugal and Spain – have been found in other research to show similar low expectations of palliative care service provision,[12] but we found more differences than similarities between these countries. In terms of prioritising life quality alone, Italy and Spain lay at opposite ends of the spectrum. Religious affiliation was associated with a lower prioritisation of quality of life in Spain (and also England and the Netherlands), but not Italy or Portugal. The prioritisation of decision-making was not similar between these countries – indeed the opposite – as Italy and Portugal lay at either end of the spectrum of views. The common assumption of regional similarities in Southern/Latin European countries versus Northern/Anglo-Saxon Europe therefore does not do justice to patent differences between countries and populations. This has implications when caring for patients from different parts of Europe in any country or setting and highlights the need for both country-specific and individualised approaches to care.

Our study has several strengths. We believe that it is the largest assessment of public priorities for treatment if faced with advanced illness to date. The study is across seven countries, is population based and used standard questions in all countries. However, limitations include our response rate – 21%. Response rates to telephone health surveys are falling and are often similar to ours, affected by technologies such as caller identification[27] and telemarketing fraud and telephone scams.[42] We attempted to increase our response rate using recommended approaches of interviewer training, establishment of researcher credentials, increasing call attempts and targeted call times.[43] The representativeness of our sample is supported by its similarity to the national populations. Although it is possible that they had different views, Kristal et al.[44] found no difference between the health behaviours and attitudes of respondents and non-respondents to a telephone survey. We do not believe that this limitation affects the clear low preference for life extension or the associated factors. Unfortunately, we could not compare respondents and non-respondents (since we randomly selected household numbers).

A further limitation is that treatment, care and information choices were based on hypothetical choices. Although decisions made in real situations can be different from

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those proposed in hypothetical situations,[45] providing contextual information (as in our study) considerably improves the agreements between choices made in real and hypothetical situations.[45] Furthermore, 50% of our sample had cared for a close relative or friend at the end-of-life; 28% described their own health as fair, bad or very bad. In the last five years, one in 10 had been diagnosed with a serious illness and 70% had experienced bereavement. Thus, many of those sampled had direct experience of the scenarios considered, which helped to place the scenario in context. In no country was health status associated with priorities. Experiences of bereavement and illness were more often associated with prioritising quality of life rather than extension. Therefore, patients might prioritise life extension even less than the low values found in our study.

In conclusion, in all seven countries, few adults (less than 6%) believe that when faced with advanced illness, such as cancer, extending life is most important and 57% or more prioritised quality of life. Cancer treatment and care needs to be reoriented towards these views and should address top priorities including providing information, dying in place of choice, relief of symptoms and supporting relatives and friends. Future guidelines should include these priorities, to enable more appropriate treatment choices for patients. The findings indicate a need in cancer care for education and palliative care to become mainstream.

Acknowledgements

We are most grateful to all the survey participants. We thank the European Commission for providing the financial support needed to undertake this study; BMG Research and ZEM University of Bonn for assistance in survey administration and data collection and Joana Cadima for statistical advice. We also thank our colleagues from PRISMA including the scientific committee who contributed to the discussions and scientific review of the survey, namely, Gwenda Albers, Barbara Antunes, Ana Barros Pinto, Dorothee Bechinger-English, Hamid Benalia, Emma Bennett, Lucy Bradley, Noël Derycke, Martine de Vlieger, Let Dillen, Julia Downing, Michael Echteld, Natalie Evans, Dagny Faksvåg Haugen, Nancy Gikaara, Sue Hall, Stein Kaasa, Jonathan Koffman, Arantza Meñaca, Johan Menten, Fliss Murtagh, Bregje Onwuteaka-Philipsen, Roeline Pasman, Francesca Pettenati, Robert Pool, Richard A. Powell, Miel Ribbe, Katrin Sigurdardottir, Bart Van den Eynden, Paul Vanden Berghe and Trudie van Iersel. We thank Susana Bento, Carolina Comabella, Filomena Ferreira, Grethe Iversen, Carmen López-Dóriga, Constanze Rémi, Christian Schulz and Wessex Translations for their work in translating and back translating the questionnaires. The invaluable work of Ron Irwin, Sian Best and Mike Gover at King's College London is also highly appreciated.

This survey was undertaken as part of one of the work packages of PRISMA. PRISMA aims to provide evidence and guidance on best practice to ensure that research can measure and improve outcomes for patients and families. PRISMA activities aimed to reflect the preferences and cultural diversities of citizens and the clinical priorities of clinicians and appropriately measure multidimensional outcomes across settings where EoLC is delivered. Principal Investigator: Richard Harding. Scientific Director: Irene J Higginson.

Declaration of conflicting interests

The authors declare that there is no conflict of interest.

Funding

This work was supported by the European Commission's Seventh Framework Programme (grant number Health-F2-2008-201655) as part of the PRISMA project to co-ordinate research into EoLC in cancer.

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